

# Understanding and Addressing the Drivers of Infant Mortality in Maine

## EXECUTIVE SUMMARY

January 2020



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# Executive Summary

## Introduction

Infant mortality, defined as the death of a child under the age of one, is a “sentinel measure of population health that reflects the underlying well-being of mothers and families, as well as the broader community, and social and economic environments”.<sup>1</sup> In 1996, Maine had the lowest infant mortality rate (IMR) in the United States—4.4 deaths per 1,000 live births; 60 infants died that year. Over the next two decades, however, the IMR in Maine increased. In 2013, the IMR in Maine was 7.1, which exceeded the U.S. rate of 6.0, and moved the state to a ranking of 43rd; 91 infants died in Maine before their first birthday in 2013. Although there has been some improvement in Maine’s IMR since 2013, Maine can do better. Two states, Massachusetts and Washington, achieved infant mortality less than 4.0 in 2017, and New Hampshire’s IMR was 4.2 in 2017.<sup>2</sup>

To understand the changes and identify the drivers of the changes in IMR in Maine over the past two decades, a group of partners representing the non-profit, health care, public health and state sectors designed and implemented the Maine Infant Mortality Project. The goals of this one-year project were to identify the drivers of infant mortality (IM) in the state using quantitative and qualitative data and develop recommendations to reduce IM that reflect the populations, cultures and environment of Maine. (A complete list of definitions and acronyms is included in Appendix A)

## Methods

Mixed quantitative and qualitative methods were used to examine the changes and drivers of IM in Maine. Several sources of data were used. The two primary sources were the Maine CDC Vital Statistics birth and death files, and telephone interviews with a diverse group of 34 key informants. The key informants represented Maine state and city agencies, birth hospitals, private practices, community-based organizations, professional organizations, and news organizations. Their areas of experience and expertise included clinical areas (obstetrics, midwifery, pediatrics, neonatology, psychiatry, forensic medicine), home visiting (Public Health Nursing and Maine Families), diverse social and economic needs of vulnerable populations, child abuse and neglect, domestic violence, substance use, family planning, the emergency medical system, behavioral health, the criminal justice system, and Native American health and health care. Other sources included: the Maine CDC’s Pregnancy Risk Assessment Monitoring System (PRAMS), the Maine Children’s Alliance, Kids Count, Maine Medical Center and Northern Light Eastern Maine Medical Center NICUs, the Maine Office of the Medical Examiner, and safe sleep research conducted by Maine Medical Center and the Maine CDC. Ten telephone interviews were also held with a sample of key informants from other states to learn about successful IM strategies that they have implemented. Three in-person interviews were conducted with women who had recently delivered in order to hear about their experiences of pregnancy and birth.

The framework that we used for our research questions was a Social Ecological Model for Infant Mortality that we developed for this project. This framework includes multiple levels that contribute to an understanding of the dynamic inter-relationships between personal, community, institutional/organizational and social/political/environmental factors. We looked at the distribution of birth and infant deaths by maternal residence (county and rurality), risk factors associated with infant mortality, the causes of infant deaths, and the existing perinatal system of care in the state. The primary limitations of our study were that data were not available for all years of the study, small sample sizes in our stratifications of data, and the limitations of self-reported data that may be subject to error.

## **Findings and Discussion**

Through this project, we documented changes in birth and infant deaths and identified the primary causes and drivers of IM in Maine. IM is complex and multi-factorial, and our research showed that there was no single primary cause or driver of the increases in IM in the state; however, many opportunities were identified to improve birth outcomes.

Consistent with other areas of the country, the number births in Maine over the last two decades have fallen, particularly among adolescents, but births to older (35+) women have increased. Infant deaths in Maine, however, have seen some increases over time. The highest IMR in the state over the past two decades was in 2013. This high rate is particularly concerning in the context of other states continuing to decrease their IMRs in recent years. One important consideration, however, is that in a small state like Maine, small numbers of births and decreases in them, in combination with small increases in infant deaths, more easily result in increases in the IMR, than in larger states with many more births.

Because Maine is a state where the majority of births occur to women living in rural areas and most of the birth hospitals, albeit small hospitals, are in rural areas/counties, rurality was an important area of study for our project. Although the IMR for women living in isolated rural areas was the highest compared to women living in other rural areas and metropolitan areas, it is again important to recognize the effects of changes when the numbers of births and deaths are small.

Most of the infant deaths in Maine and in the U.S. are due to causes related to being born too early. Infants born prematurely and/or low birth weight have the highest IMR. The earlier the pre-term infant is born, the higher the mortality. There are many known risk factors for prematurity such as a history of premature birth, multiple pregnancy, short pregnancy interval, tobacco use, other substance use, obesity, chronic conditions such as diabetes, maternal infections, and stress. Many of these risk factors are amenable to change through medical interventions, but also through behavioral interventions (for example smoking cessation programs) and social support.

The second and third major causes of infant deaths in Maine are congenital anomalies (birth defects) and SIDS/SUID (Sudden Infant Death Syndrome/Sudden Unexpected Infant Death), respectively. The causes of congenital anomalies are often genetic or unknown (the causes of 75% of congenital anomalies are unknown and therefore more difficult to address). However, many SIDS/SUID deaths are associated with unsafe sleep practices, and therefore may be amenable to interventions such as Maine Department of Health and Human Services/Maine CDC Safe Sleep

Campaign ([safesleepforme.org](http://safesleepforme.org)) currently underway, enhanced education in clinical and other sites, and the Cribs for Kids program. Other causes of infant death—infections, injuries and other perinatal conditions and causes—were less stable over our period of study (due in part to small numbers), but also saw some increases.

In examining risk factors (drivers) of infant mortality, we identified several established factors associated with Maine infant deaths. These include: demographics (maternal age, maternal education, marital status, race/ethnicity), clinical considerations (multiple pregnancies, adequacy of prenatal care, obesity, mental health conditions), substance use (tobacco smoking, marijuana, alcohol, opioids and other substances), and other issues (domestic violence, unsafe sleep practices and social determinants of health).

Although demographics cannot be changed, the information about their relationships to IM may be used for targeted outreach, education and consideration in practice. For example, births to older women have been increasing at the same time that the IMR in this group has been increasing so this might be a group to target with additional information and/care such as referrals to high-risk obstetricians. Another example is marital status; we found higher IM among unmarried women compared with married women. The higher IMR among Black/African American, compared to White women and other groups, is also an important finding to consider. In the U.S., Black/African American women have consistently had 2–2.5 times higher IMR, compared to White women; and as Maine becomes more diverse, this may be an important measure to monitor.

We identified several risk factors related to clinical care and services. We found increased IM among multiple births, and among women with inadequate prenatal care, obesity, and depression. Other identified risk factors included: cigarette smoking, alcohol use, marijuana use, unsafe sleep practices, and domestic violence. Although quantitative data are not currently available linking social determinants of health to infant mortality, our key informant interviews identified issues such as poverty, unstable housing, hunger and transportation as important IM risk factors that need increased focus.

Results from this project allowed us to define the components of an ideal perinatal system of care for Maine. Examining the current system, we found fragmentation in the continuum of care, a lack of coordination across components, and barriers to services particularly in rural areas. Our findings reveal several opportunities for improvement. These include:

- Improved access to primary care for women before and between pregnancies,
- More perinatal screenings,
- Enhanced mechanisms in place to ensure risk-appropriate care,
- Improved access to mental health services,
- New models of care for women with substance use disorder,
- Strategies to ensure that all families that qualify for programs like Public Health Nursing, Maine Families and WIC enroll in these programs,
- New or enhanced strategies to address perinatal labor shortages and access to maternity services in areas where these services have closed such as rural areas,
- Increased access to specialists,

- Increased provider trainings,
- Increased family engagement and education,
- Stronger communication and collaboration between primary and specialty care providers who share patients, and
- Increased number of statewide and regional activities designed to improve the quality of care and outcomes for mothers and infants.

We also identified a number of assets and strengths to build upon, such as the statewide Perinatal Quality Improvement for Maine (PQC4ME) that includes birth hospitals across the state; the new Children’s Cabinet that brings together all state agencies involved in child-related policy and initiatives; longstanding partnerships between the Maine Department of Health and Human Services, the Maine CDC and private sector physicians, hospitals and others; and providers of all types across the state who are deeply committed to ensuring that Maine pregnant women, infants and children experience the best possible outcomes.

## **Recommendations**

We propose recommendations that are summarized below by the strategic areas outlined in the Ideal Comprehensive Perinatal System of Care for Maine framework developed through this project. The strategies include: 1) Infrastructure to Support the Strategies and Actions for the Ideal Comprehensive Perinatal System of Care for Maine; 2) Access to Services; 3) Workforce and Training; 4) Referrals, Coordination and Collaboration; 5) Family Engagement and Education; 6) Policies and Programs; and 7) Assessment, Monitoring and Evaluation. More information about the recommendations is provided in the full report.

### **Proposed Recommendations by Strategy**

#### **STRATEGY 1 Infrastructure to Support the Strategies and Actions for the Ideal Comprehensive System of Perinatal Care in Maine**

- 1.1 Establish and maintain a Work Group.**
- 1.2 Determine a perinatal regionalization approach for the State of Maine to ensure access to risk-appropriate care for mothers and infants.**
- 1.3 Align and coordinate the Work Group with the Maine CDC MCH Block Grant and the MFIMR (Maternal, Fetal, Infant, Mortality Review) panel to enhance the efforts across these entities and avoid duplication.**
- 1.4 Align and coordinate the Work Group with the work of the PQC4ME to enhance the efforts across these entities.**
- 1.5 Align and coordinate the Work Group with the work of the Maine Rural Transformation Team and similar high-level state initiatives to enhance the efforts across these entities.**

- 1.6 Incorporate into all strategies and actions considerations of cultural sensitivity and bias (structural and implicit), as appropriate.**

## **STRATEGY 2 Access to Services**

- 2.1 Design and implement a study to identify the areas of the state, particularly the rural areas, where gaps in services related to perinatal health exist.**
- 2.2 Prioritize, design and implement new or enhanced models of care/services.**
- 2.3 Identify and implement perinatal risk assessment and screening tools, and resources to address the results of the assessments and screenings.**

## **STRATEGY 3 Workforce and Training**

- 3.1 Design and implement strategies/models to fill the identified workforce shortages (clinical, mental health, substance use) across the state.**
- 3.2 Design, implement and evaluate trainings for perinatal providers.**
- 3.3 Design, implement and evaluate trainings for providers who see perinatal populations, but whose focus is not perinatal populations.**
- 3.4 Design, implement and evaluate trainings or modules on perinatal topics for students.**

## **STRATEGY 4 Referrals, Coordination and Collaboration**

- 4.1 Establish written procedures and agreements for maternal and neonatal referrals and transports between community-based birth hospitals and providers, and Level III/V hospitals.**
- 4.2 Establish and implement mechanisms for referrals to community-based programs and services such as Early Intervention (EI) at perinatal care sites (hospitals and practices).**
- 4.3 Coordinate and collaborate (including the sharing of results) on perinatal activities such as PQC4ME QI (Quality Improvement) projects at the birth hospitals and birth centers.**

## **STRATEGY 5 Family Engagement and Education**

- 5.1 Conduct and assess provider trainings on family engagement and shared decision-making.**
- 5.2 Create a comprehensive package of maternal/family education materials.**

## **STRATEGY 6 Public Policies and Programs**

- 6.1 Design and implement an analysis of eligibility (including opportunities for expanding eligibility), participation, services and costs for public programs that can optimize maternal and infant outcomes.**



- 6.2 Examine payment strategies, provider performance incentives and quality improvement initiatives to improve birth outcomes and lower costs.**
- 6.3 Implement and evaluate evidence-based public social media campaigns on select perinatal topics.**
- 6.4 Ensure that eligible women and their families receive the services that promote optimal birth outcomes.**
- 6.5 Design and implement a website of perinatal resources.**

#### **STRATEGY 7 Assessment, Monitoring, and Evaluation**

- 7.1 Assess the effectiveness of new and enhanced models and activities using QI methods and data collection, and/or other appropriate evaluation methods.**
- 7.2 Develop and distribute regular public health reports or dashboards of maternal and infant outcomes.**
- 7.3 Enhance the MFIMR panel reviews and reporting.**
- 7.4 Improve Vital Statistics data, including accuracy, timeliness and reporting.**

## **Summary**

Through this project, we were able to describe the trends in births and IM in Maine over the period 2000–2017. We identified the primary causes, and many associated demographic, clinical and other risk factors. We explored the perceptions of a diverse group of experts from across the state about the risk factors they think are important, and how Maine’s existing system of perinatal care is working and how it can be improved. Finally, we identified recommendations that address the findings of the report and if implemented, will improve Maine’s IMR as well as birth outcomes overall.

While recognizing that the gaps and needs identified in this report are real and substantive, we clearly heard that many are committed to not only improving Maine’s IMR but birth outcomes for all infants and families across the state. It is our hope that the findings and recommendations will help inform and guide the process of engagement and action.